

## **Title Page**

**Title of Project:** Understanding and Honoring Patients with Multiple Chronic Conditions

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## Structured Abstract

### **Purpose:**

To determine the core design elements of a shared and interactive priority plan for patients living with multiple chronic health conditions.

### **Scope:**

In this project, experts in chronic disease care, health information technology, and participatory design methods studied how patients with multiple chronic conditions understand and set priorities for care. The results were used in a design process in which patients, their family caregivers, and their healthcare providers developed specifications for an interactive priority plan to be shared between patients and providers.

### **Methods:**

Our care framework is based on the elements of Collaborative Care and the Chronic Care Model. The design approach used participatory design and the partial perspectives framework.

We focused on patients who have diabetes and at least two of the following three common chronic conditions: osteoarthritis, coronary artery disease, and depression. We accomplished Aim 1 first through home visits with patients and family caregivers and, second, through shadowing and interviewing patients, caregivers and providers together in the clinic. For Aim 2, we engaged patients and providers in a participatory design process focused on developing design principles and specifications for care planning which honored patients' needs, abilities and preferences.

### **Results:**

Analysis of home visits, interviews and photo elicitation of patients and family members revealed six domains of what patients described as most important for their well-being and health: principles, relationships, emotions, activities, abilities, and possessions. These personal values were interrelated and rarely expressed as individual values in isolation. In a follow-up telephone survey, we found this framework of personal values generalized to a new set of patient participants and that the domains of the framework can be used to elicit a breadth of potential values of individuals with multiple chronic conditions. We then used these results to inform subsequent co-design activities with patients, providers and caregivers. These co-design activities identified the following seven dimensions needed in the design of care planning for patients with multiple chronic conditions: explicitness, effort, disclosure, guidance, intimacy, scale, and synchrony. We then use these findings to develop initial specifications for the tools, roles and processes needed to support interactive priority planning.

**Key Words:** patient-provider communication, chronic illness care, care management, multimorbidity

## **PURPOSE**

The overall goal for this project was to determine the core design elements of a shared and interactive priority plan for patients living with multiple chronic health conditions.

Specific Aims were:

Aim 1: The first aim of the project was to establish patient needs, preferences and capabilities for an interactive healthcare priority plan. We first described how patients decide on and support their priorities for care including an initial model of priority setting.

Aim 2: The second aim of the project was to engage patients, family caregivers and providers in design to establish validated requirements for the interactive priority care plan. After gaining an understanding of how priority-setting occurs in the home and in the clinic, we developed specifications for a shared, interactive priority care plan. The primary goal of this Aim was clarifying users' needs for priority setting and fulfillment in the context of daily life, rather than developing a fully functional system. This aim also included an evaluation of the participatory design methods for their utility in the project and potential applicability in future chronic care.

## SCOPE

### Background

Patients with multiple chronic conditions are a growing public health concern. One in four Americans have two or more chronic conditions, defined as lasting a year or more, requiring ongoing medical attention, and/or limiting the activities of daily living. For people over 65 years old, multimorbidity is the standard, with two-thirds having two or more major chronic health conditions. Approximately 65% of total healthcare spending in the United States is for individuals with two or more chronic diseases. Despite this high spending, these patients often receive inadequate care, including conflicting medical advice. They experience poor quality of life, physical disabilities, adverse drug events, and higher mortality than patients without multimorbidity. Improving the health and care of individuals with multiple chronic conditions is a major priority.

### Context

Patients with multiple chronic conditions receive more conflicting medical advice, and experience worse quality of life, more physical disability, more adverse drug events, and higher mortality than those without multimorbidity. Unlike acute health conditions, chronic health conditions are primarily managed by patients and their families. Avoiding the complications of the most common chronic health conditions such as diabetes, arthritis and depression requires patients to self-manage daily activities such as eating a specific diet, getting physical activity, and taking medications. Unfortunately, these self-management activities can be in conflict. For example, shortness of breath from asthma can impede ability to exercise for diabetes care, and the psychological stress of one condition can aggravate other conditions. Clinical guidelines for individual chronic conditions often do not consider the needs of multimorbidity patients and can have adverse outcomes in this population. Patients must also juggle self-management activities within the context and resources of other demands. Money, time and the availability of a family caregiver all influence patients' self-management choices, particularly among vulnerable populations.

Compared to providers, patients are more likely to prioritize symptoms over management of asymptomatic diseases associated with future disability or death, such as high blood pressure. Providers may develop an initial conceptualization of care priorities that is biased towards the more medical aspects of a diagnosis such as severity and prognosis. The discordant mental models of patients and providers about care priorities may undermine collaborative problem identification and priority setting in chronic illness care.

To get the best care, patients with several chronic illnesses must communicate what is most important to them to their doctors and other healthcare providers, and doctors must understand and support patients' priorities for care. Choosing the right care priorities for patients with multimorbidity is important since the ability to self-manage competing demands can affect the quality and length of life. Unfortunately, we often do not talk to patients about their priorities or make them a part of care. We need care plans that include patients' priorities and tools for sharing them with all caregivers. But first, we must understand what shapes the priorities of patients with multiple chronic conditions and how these priorities can be supported by healthcare providers.

### Settings

This study was conducted at Kaiser Permanente Washington (formerly Group Health), an integrated care delivery system with nearly 600,000 members in Washington State. The study was restricted to the 391,749 members who receive primary care at one of Kaiser Permanente Washington's 25 owned-and-operated clinics. At the time of the study, Kaiser Permanente Washington membership included 55,239 Medicare members, 19,089 Medicaid members, and 11,623 covered by the Basic Health Plan (a state-supported insurance program for low-income families). The Kaiser Permanente Washington population is generally similar to that of the surrounding area. Kaiser Permanente Washington has a slightly higher proportion of women (53%) than the regional community (50%) and the nation (51%). Kaiser Permanente Washington members are also older (46% ≥45 years) than the regional community (38%) and the nation (39%). Compared to the rest of the country, Kaiser Permanente Washington

members are more likely to be Asian or Pacific Islanders (12% versus 4%), but less likely to be African American (6% versus 12%) or report Hispanic ethnicity (6% versus 15%). The Kaiser Permanente Washington racial and ethnic composition broadly represents the Puget Sound region. In the proposed study, we purposively sampled the Kaiser Permanente Washington population to achieve educational status similar to the U.S. population and oversampled racial and ethnic populations (see Participants below for details).

Kaiser Permanente Washington uses an ambulatory electronic health record (EHR) system (EpicCare). In 2003, Group Health (now Kaiser Permanente Washington) implemented a patient website that is integrated with its EHR (EpicCare). The patient Website allows patients to exchange electronic messages with their entire healthcare team; access portions of their EHR in real time, including provider visit notes, laboratory studies, problem lists, medication lists, allergy history and immunization history; obtain after-visit summaries with hyperlinks to the Healthwise knowledge base; obtain refills on medications with free shipping; schedule office appointments with providers; and create a comprehensive Health Risk Assessment profile. In 2011, these features were extended into mobile applications for the iPhone and Android smart phones.

## Participants

We engaged a single cohort of patients with multiple chronic conditions and a sample of family caregivers. Patients had diabetes and at least two of the following three common chronic conditions: depression, osteoarthritis, and coronary artery disease. For all stages of the study, we purposively sampled patients with minority racial and ethnic backgrounds in order to more closely align our participant group with the demographics of the overall US population. Between 26- 32% of our study populations in Aim 1 had high school or less educational level in Aim 1 (see Tables 1 and 2).

**Aim 1:** We first described how patients with multiple chronic conditions understand and set priorities for care. We did this in three stages. First, we conducted home visits with patients and a sample of caregivers. **Table 1** shows participant characteristics for home visits.(1) Second, we observed enrolled patients during primary care visits and conducted pre/post interviews with patients and their caregivers, and separate post interviews with the primary care team. Participants for in this phase included: nine PCPs, six medical assistants; one otolaryngology specialist; sixteen patient participants; and seven informal family caregivers who attended visits with patients.(2) Finally, we conducted validation phone interviews with 54 patients including those enrolled in previous phases of the study (n = 17) and patients new to the study (n = 37) (**Table 2**).

	<b>Patient participants (n=31)</b>	<b>Family member participants (n=19)</b>
<b>Age</b>	68.7	N/D
<b>Gender</b>		
Female	14	9
Male	17	10
<b>Race/Ethnicity</b>		
White/Caucasian	24	18
Black/ African American	2	1
Asian American or Pacific Islander	1	0
Native Hawaiian or Pacific Islander	1	0
White and Native American/Alaskan native	2	0
Hispanic	1	0
<b>Education</b>		
8 <sup>th</sup> grade or less	0	1
Some high school, not a graduate	3	0
High school graduate or GED	7	5
Some college or 2-year degree	14	10
4-year college degree	1	1
More than 4-year college degree	6	2

**Aim 2:** The second aim of the project engaged patients, family caregivers and providers in participatory design activities to establish validated requirements for the interactive priority care plan. Aim 2 had two stages of patient and provider engagement. In the first stage, we engaged three groups of patients and caregivers, and three groups of primary care team members in sequential futures workshops and participatory design sessions. Study cohorts included 7 PCPs, 8 MA, 3 RN and 24 patient participants.(4) In the second stage, we invited patient/caregiver and provider groups to give feedback on a prototype of a shared priority plan. Three patient/caregiver groups were engaged – two composed of participants who participated in the study previously, and one composed of participants new to the study. Three primary care team groups were also engaged – two groups who had participated previously, and one group new to the study. The groups included 11 PCPs, 11 MA, and 1 RN and 35 patient participants.(4)

**Incidence and Prevalence**

Measuring incidence and prevalence was not part of this study.

**Table 2: Participants in Values Framework Evaluation (Aim 1)(3)**

	Patient participants (n=54)
<b>Age</b> mean (SD)	65.4 (10.7)
<b>Gender</b> n (%) Female	31 (57.4%)
<b>Race</b> n (%)	
American Indian/Alaska Native	1 (2%)
Asian	4 (7)
Black/African American	6 (11)
Native Hawaiian/Pacific Islander	1 (2)
White	31 (57)
More than one race	8 (15)
Other	3 (6)
<b>Hispanic/Latino</b>	5 (9%)
<b>Education</b>	
Some high school, not a graduate	4 (7%)
High school graduate or GED	10 (19)
Some college or 2 year degree	24 (44)
4-year college degree	5 (9)
More than 4-year college degree	11 (20)

**Methods**

**Study Design**

We used mixed methods grounded in a user centered design approach. Specific methods included including ethnographic interviews, photo elicitation, home tours, participatory design workshops, and prototype testing.

**Statistical Analysis**

Statistical analysis was only applicable for the analysis of the value framework with patients. All other analyses were qualitative. For the analysis of the value framework, we used chi squared test to determine whether participants rated the importance of values differently across the six domains of the framework. (3)

**Data Sources/Collection**

Data sources included the following: transcribed interviews; photos by participants; field notes from home visits; surveys of the value domains; demographic surveys; recordings, artifacts, transcripts and notes from participatory design workshops; audio recordings, transcripts and notes from prototype testing sessions.

**Interventions**

We had no interventions.

## Measures

Survey measures were used only for the analysis of the value framework. This included a 1 to 5 rating of importance (important to most important) of each value elicited from patients.(3) All other data and analysis was qualitative.

## Limitations

In Aim 1, we may not have captured the entirety of patients' personal values. Patients with different socioeconomic circumstances than those reflected here might describe different values. In addition, the study reflects the unique perspectives of patients struggling with diabetes and a specific constellation of other chronic conditions, including depressive symptoms. Future work is needed to assess the transferability of these value domains across diverse groups of patients, including individuals who do not have diabetes or who are uninsured, unemployed, or in unstable housing situations. During observations of patients and providers, it is possible that participants behaved differently based on their perception of the purpose of the study. In the participatory design and prototype testing of Aim 2, patient participants with different chronic conditions or socioeconomic or cultural backgrounds may also have given different results. Health care provider teams from a less integrated healthcare system may also have provided different contributions and evaluations in this phase of the study.

## Results

### Principal Findings

We summarize our principle findings by Aim below and then by core design principles. Further details are in peer reviewed publications (6 published papers, 2 published posters, 1 paper in submission). Results in submission have more detail below.

**Aim 1:** Establish patient needs, preferences and capabilities for an interactive healthcare priority plan. We described how patients decide on and support their priorities for care including an initial model of priority setting.

To begin work, we engaged patients and family care givers at home to understand how patients thought about and developed personal values on what is most important to wellbeing and health. This work was foundational for developing tools that could elicit from patients what is most important to their wellbeing and health.

1. *Understanding What Is Most Important to Individuals with Multiple Chronic Conditions: A Qualitative Study of Patients' Perspectives* (published paper(1)and poster(5)). Analysis of home visits, interviews and photo elicitation of 31 patients and 19 of their family members revealed six domains of what patients described as most important for their well-being and health: principles, relationships, emotions, activities, abilities, and possessions. Personal values were interrelated and rarely expressed as individual values in isolation. These domains describe the range and types of personal values multimorbid older adults deem important to well-being and health. The paper describing this work, published in the Journal of General Internal Medicine, had an accompanying editorial highlighting the importance of our work for clinical care. (6)
2. *Eliciting Values of Patients with Multiple Chronic Conditions Evaluation of a Patient-centered Framework* (published paper).(3) In this paper we reported results from a survey evaluating how well the values framework described above generalized beyond the field study participants, and how well the framework supports values elicitation. We found that respondents frame values in a way that is consistent with the framework, and that domains of the framework can be used to elicit a breadth of potential values individuals with multiple chronic conditions. These findings demonstrate how a patient-centered perspective on values can expand on the domains considered in values clarification methods and facilitate patient-provider communication in establishing shared care priorities.

3. *"It Just Seems Outside My Health": How Patients with Chronic Conditions Perceive Communication Boundaries with Providers* (published paper).(7) This paper examined the various motivations and factors that explain communication boundaries between patients and their healthcare providers with regard to patients personal values. Patients' disclosures reflected perceptions of what was pertinent to share, assumptions about the consequences of sharing, and the influence of interpersonal relationships with providers. Our findings revealed limitations of existing approaches to support patient-provider communication and identified challenges for the design of systems that honor patient needs and preferences.
4. *Getting Traction When Overwhelmed* (published poster).(8) This poster sought to understand how participants perceived relationships among their values and their health concerns. We found that participants felt overwhelmed by multiple concerns, but were able to surmount these feelings when they pursued values that were linked to self-care. We discuss implications for incorporating values into patient-provider communication.
5. *How Values Shape Collaboration Between Patients with Multiple Chronic Conditions and Spousal Caregivers* (published paper). (9) This paper, analyzing home visit data on 12 dyads of patients and spousal caregivers, identified partners' values and how they shape the collaborative management of multiple chronic conditions. Partners' coinciding values motivated them to empathize with and support each other in the face of challenges related to health and well-being. When their values were asymmetric, they perceived tensions between individual autonomy and their ability to coordinate with their partner. Systems to support partners in this context could help them overcome asymmetric values, but should balance this with support for individual autonomy.

In the second part of Aim 1, we observed patients and health care providers to understand the roles and opportunities of personal values in current clinical care.

6. *"It's good to know you're not a stranger every time:" Communication about Values Between Patients with Multiple Chronic Conditions and Healthcare Providers* (published paper). (10) We report on the extent to which certain categories of patients' personal values identified in prior research were discussed in clinic visits. We then discuss how patients and providers coordinated their perspectives to establish connections among patients' personal values and health concerns. These findings have implications for the design of systems to support patient-provider communication to incorporate patients' values and promote concordant priorities for health care.
7. *Creating Conditions for Patients' Values to Emerge in Clinical Conversations: Perspectives of Health Care Team Members* (published paper). (2) This paper reports a practice-based account of ways in which providers engage with patient values, and discusses how future work in interactive systems design might extend and enrich these engagements. We found care teams engage with patients' values both for personalizing care and to create strong relationships with patients. We also found avenues for encouraging routine communication about values, such as extending values elicitation instruments for providers to elicit a broader range of topics, and educating patients about the ways providers use patients' values to personalize care. These findings also revealed that care team members sometimes face a dilemma between communicating with other team members about patient values and protecting patient privacy.

**Aim 2:** Engage patients, family caregivers and providers in design to establish validated requirements for the interactive priority care plan. After gaining an understanding of how priority-setting occurs in the home and in the clinic, we developed specifications for a shared, interactive priority care plan. The primary goal of this Aim was clarifying users' needs for priority setting and fulfillment in the context of daily life, rather than developing a fully functional system.

8. Supporting Communication About Values Between People with Multiple Chronic Conditions and



their Providers (paper in revision for CHI 2019).(4) To support care guided by patient personal values for wellbeing and health established in Aim 1, we conducted a two-part study with the following key stakeholders in the care of patients with multiple chronic conditions: patients, informal caregivers, and providers. This work was informed by patient and provider user needs assessments in Aim 1. In Part I of the study, co-design activities generated seven dimensions that characterize stakeholders' diverse ideas for design of interactive priority planning: explicitness, effort, disclosure, guidance, intimacy, scale, and synchrony. In Part II, we used the dimensions to design three concept storyboards and presented them in focus groups to further scrutinize findings from Part I. Based on these findings we provide direction to improve care planning based on better patient-provider communication about each patient's personal values for wellbeing and health.

### **Interactive Priority Care Planning: Tasks, Tools and Roles**

Based on the combined analyses and publications above, we outline below an initial set of principles for designing tools, tasks and roles for eliciting and honoring what is most important to the wellbeing and health of patients living with multiple chronic health conditions. Our work in aim 1 suggested we should focus on designing an ongoing, interactive care planning process enabled by tools, people, processes. The process for identifying priorities for care should be iterative involving self-reflection by patients and facilitated by conversations with healthcare providers and family members. These initial set of principles are below:

#### **Invite patients to share what is most important to them for wellbeing and health.**

Our results suggest that providers who invite patients to share personal values will enhance relationships with patients, foster patient self-reflection and self-awareness. This activity may also enhance provider empathy and ultimately promote concordance between patients and providers on care priorities.

#### **Personalize probes for personal values according to a patient's needs and abilities.**

We found that most patients could articulate their personal values in short statements when asked probes that included our six domains. Some patients, though, may better express personal values through photographs, stories or other means. In all elicitation techniques, using the probes from the six domains helps enable patients to focus on what is most important for wellbeing and health in daily life. These domain probes can also help support more efficient elicitation and sharing of personal values compared to less explicit elicitation techniques.

#### **Use six domain probes to help elicit personal values.**

The six domains for personal value probes provide a useful template for eliciting values not typically discussed in clinical contexts. Patients perceive many personal values as not pertinent to clinical conversations, or they worry about the consequences of sharing personal values with providers. If asked only an open-ended question, many patients also tend to describe healthcare processes such as the ability to get in to see their doctor in a timely manner. The question domains help center patients on what is most valued in their daily lives. After being primed with questions from the six domains, an open-ended follow-up question on what else is important for wellbeing and health can help uncover additional values not encompassed by the domains.

#### **Probe for overlap and symbiosis across personal values.**

Understanding how values relate to one another can enable a patient's self-awareness of what is most important; help patients feel recognized by providers, and allow provider awareness of priorities in a patient's life.

#### **Probe for relationships between social determinants of health and personal values.**

Financial insecurity, social isolation and other social determinants may have a substantial impact on a patient's ability to realize or maintain personal values. In other cases, personal values overlap with current conceptualizations of social determinants (e.g., social support).

Identifying these relationships between values and social determinants can help prioritize care plans. We began to see some of these relationships in our project; however, further research and implementation is needed.

**Honor patient preferences for disclosure of personal values.**

Patients are cautious about sharing information, such as personal values, based on assumptions about actions that providers might take. Some of our patient participants described knowingly omitting information about the emotional aspects of managing chronic health conditions. Prompts for disclosures in the course of patient-provider communication could likely surface certain topics that patients might never express without encouragement. The nature of the prompt is critical to setting the right context for breaking down assumptions. Clarifying some of these fears and addressing questionable assumptions could reduce the burdens of sharing. The ability of healthcare providers to honor patient preferences relies on an awareness of those preferences. At the same time, patients need to be assured that making their sharing preferences transparent will help honor their needs to maintain communication boundaries.

**Ensure patients personal values are heard and acknowledged in a caring environment.**

Participants want the personal values they share acknowledged by providers in an honest and caring way. Failure to acknowledge any personal values shared by a patient could also disrupt the relationship.

**Link personal values to meaningful outcomes and care plans.**

During our study, we observed occasions when providers made clear and meaningful connections between a care plan and personal values. These examples highlight both the current capability of providers to make these links and the opportunity for providers to extend these connections to patients broader set of personal values during care plans and follow-up. A shared understanding of the spectrum of a patient's personal values should help build patient and provider concordance on priorities for care.

All publications and other products from the study are available on our study website. <http://vitalresearchstudy.org> This constellation of publications describes results and design recommendations needed to develop and test care programs which elicit and honor the personal values of those living with multiple chronic conditions.

**Discussion**

The findings of this project helped address a critical junction in designing care that elicits and honors what is most important to patients living with multiple chronic conditions. We developed recommendations that can be used by healthcare providers, healthcare researchers as well as health information technology developers. Kaiser Permanente Washington, for example, four primary care teams are using the tools, processes and roles developed in this grant to pilot test the feasibility and acceptability of care guided by patients' personal values. The value of our work was also emphasized by the enthusiasm received in its publication including an accompanying editorial in the Journal of General Internal Medicine.(6)

Grounding our project in the approach and methods of user centered design allowed us to identify unexpected challenges and opportunities for designing care that elicits and honors what is most important to patients. We entered the grant believing that the sole focus of the project should be to understand how to elicit values from patients and then support patients and providers to apply those values to care decisions. We came out recognizing that eliciting and sharing patient values is deeply intertwined with the development of patient-provider relationship. Patients highly value this relationship. If patients share those personal values, providers must be ready to acknowledge them. Patients must also feel safe to disclose those values to providers, even when they may not recognize how a value relates to care. Healthcare systems must create the time, space and tools to enable these conversations.

We found the act of asking what was most important to patients' wellbeing and health during our in-depth home visits initiated substantial self-reflection and, in several patients, new self-awareness. Following these visits, we recognized this activity as the first, and perhaps the most critical step, in establishing priorities for care. The invitation and expression of personal values in patients own words provides a level of visibility, acceptance and deliberation that may be essential for good chronic care planning. Several participants also described the value of the activity on its own. In some patients, articulating personal values prompted a reconsideration of priorities in their daily lives. The importance of this first step in care planning prompted us to develop a deeper understanding of patient needs and preferences for eliciting and sharing personal values.

Our recommendations for eliciting personal values are unique but complementary to other approaches to eliciting values in late in life care planning. Other value based tools for late in life planning often ask about tradeoffs in quality of life concepts, such as between comfort and consciousness or quality versus length of life. In contrast to these other approaches, our intent was to elicit the spectrum and interrelatedness of what each person identifies is most important in his or her own words. For example, our framework is agnostic about whether a person identifies the same thing in two different dimensions of personal values (e.g. a person may identify 'going to church' as an activity or an ability). The goal is to elicit and support a shared awareness of the spectrum of what is most important to the patient, regardless of which domains in the framework elicited which personal values.

As we move to the next steps in care planning, we expect that our approach to eliciting personal values will require developing healthcare roles and processes to identify meaningful and measurable outcomes linked to a patient's personal values. This is new territory in the care of patients with multiple chronic conditions. In our team, we have started on this next step in three follow-up projects including a grant from NLM (1R01LM012813-01). Following our presentation to the AGING Initiative Steering Committee, Drs Aanand Naik and Mary Tinetti also shared with us their recent work with values guided care among patients with multiple chronic conditions.(11) The complementary approaches of our teams should help guide improvements in the care and lives of patients living with multiple chronic conditions.

### **Conclusions**

Current systems of care are not meeting the needs of older patients with multiple chronic health conditions. Improving care for these patients requires understanding and honoring what is most important to them. This will require: eliciting a comprehensive set of a patient's personal values at different points over time; honoring patients' disclosure preferences for personal values; giving healthcare providers tools and conversational probes to encourage patient disclosure of personal values; and new information technology which highlights personal values to guide care planning.

### **Significance**

This project addressed a critical junction in the design of care for patients living with multiple chronic conditions. These patients receive more conflicting medical advice, and experience worse quality of life, more physical disability, more adverse drug events, and higher mortality than those without multi-morbidity. Patients with multiple chronic conditions often face competing and conflicting health demands. To get the best care, patients with several chronic illnesses must communicate what is most important to them to their doctors and other healthcare providers, and doctors must understand and support patients' priorities for care. In this study, we developed key elements needed to guide care planning that supports what matters most to patients living with multiple chronic conditions. Many of our findings challenge current care practices and norms in caring for patients with complex needs.

Our publications, described above with links on our project website, provide the detail needed for others to develop and test their own care programs for eliciting and honoring the personal values of those living with multiple chronic conditions. The grant has provided the foundation to enable a patient centered approach to ensure that personal values guide the care choices of those living with multiple chronic conditions.

## Implications

Many of our findings can be applied immediately to the design of both healthcare delivery and health information technology. Simple changes during healthcare visits, such as asking patients about what is important to them by using the personal value domains established in our project could lead to better relationships with providers and more informed conversations about priorities for care. Other providers may choose to reach out to patients before a planned visit with one or more of the elicitation tools we developed (e.g., survey or photo) to gain a more comprehensive picture of patients values to guide care planning. Our findings also provide guidance on care conversations which honor patient preferences for disclosure boundaries. Better care for patients with multiple chronic conditions will only occur when patients feel that their values will be recognized by providers and honored in their care.

The results of our study highlight many of the larger challenges remaining for the design of better care planning in patients with multiple chronic conditions. We heard consistently that patients are worried about imposing any extra time on their healthcare providers. We also heard the associated concern that many of the things patients see as most important to wellbeing and health do not seem relevant to conversations about their healthcare. Current healthcare systems reinforce this perception. Chronic care decisions are driven largely by focusing on outcomes related to individual medical diagnoses rather than what a patient expresses as most important. The resulting discordance in care priorities between doctors and patients with multiple chronic conditions yields not only poor care but likely waste. Patients seek more care when needs are not met. Taking time up front to understand a patients' values and honor them in care may improve both the quality and efficiency of care.

Our findings highlight the importance of promoting innovations which support care guided and measured by the personal values of patients with multiple chronic conditions. Realizing care guided by personal values will require substantial sociotechnical innovation in healthcare systems that have historically been mostly entrenched in disease focused care and in symptom management (e.g., palliative care). Our results describe a well-grounded approach to initiating interactive care planning. Testing and potentially disseminating this approach will require not just new processes but developing new norms of patient-provider communication, new outcomes and new opportunities for care.

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10. Berry ABL, Lim C, Hartzler AL, Hirsch T, Ludman E, Wagner EH, Ralston JD, editors. "It's good to know you're not a stranger every time": Communication about Values Between Patients with Multiple Chronic Conditions and Healthcare Providers. CSCW Conf Comput Support Coop Work; 2017.
11. Naik AD, Martin LA, Moyer J, Karel MJ. Health Values and Treatment Goals of Older, Multimorbid Adults Facing Life-Threatening Illness. *J Am Geriatr Soc.* 2016;64(3):625-31. doi: 10.1111/jgs.14027. PubMed PMID: 27000335; PMCID: PMC5001155.

## List of Publications and Products

### Publications:

1. Lim CY, Berry ABL, Hirsch T, Hartzler AL, Wagner EH, Ludman EJ, Ralston JD. Understanding What Is Most Important to Individuals with Multiple Chronic Conditions: A Qualitative Study of Patients' Perspectives. *J Gen Intern Med.* 2017;32(12):1278-84. doi: 10.1007/s11606-017-4154-3. PubMed PMID: 28849368; PMCID: PMC5698221.
2. Berry ABL, Lim C, Hartzler AL, Hirsch T, Ludman E, Wagner EH, Ralston JD. Creating Conditions for Patients' Values to Emerge in Clinical Conversations: Perspectives of Health Care Team Members. *DIS (Des Interact Syst Conf).* 2017;2017:1165-74. doi: 10.1145/3064663.3064669. PubMed PMID: 28890950; PMCID: PMC5589444.
3. Berry A, Lim C, Hartzler A, Hirsch T, Ludman E, Wagner E, Ralston J. Eliciting Values of Patients with Multiple Chronic Conditions: Evaluation of a Patient-centered Framework. *AMIA Annual Symposium Proceedings*2017.
4. Lim C, Berry ABL, Hirsch T, Hartzler AL, Wagner EH, Ludman E, Ralston JD. "It just seems outside my health": How Patients with Chronic Conditions Perceive Communication Boundaries with Providers. *Proceedings of the 2016 ACM Conference on Designing Interactive Systems*; Brisbane, QLD, Australia. 2901866: ACM; 2016. p. 1172-84.
5. Berry ABL, Lim C, Hirsch T, Hartzler AL, Wagner EH, Ludman E, Ralston JD. Getting Traction When Overwhelmed: Implications for Supporting Patient-Provider Communication. Companion of the 2017 ACM Conference on Computer Supported Cooperative Work and Social Computing; Portland, Oregon, USA. 3026328: ACM; 2017. p. 143-6.
6. Berry ABL, Lim C, Hartzler AL, Hirsch T, Wagner EH, Ludman E, Ralston JD. How Values Shape Collaboration Between Patients with Multiple Chronic Conditions and Spousal Caregivers. *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems*; Denver, Colorado, USA. 3025923: ACM; 2017. p. 5257-70.
7. Berry ABL, Lim C, Hartzler AL, Hirsch T, Ludman E, Wagner EH, Ralston JD, editors. "It's good to know you're not a stranger every time": Communication about Values Between Patients with Multiple Chronic Conditions and Healthcare Providers. *CSCW Conf Comput Support Coop Work*; 2017.

### Posters and Presentations:

1. Berry A, Lim C, Hirsch T, Hartzler A, Wagner E, Ludman E, Ralston J. Toward Honoring the Values of Patients With Multiple Chronic Conditions. Poster at AMIA Annu Symp; November 12-16; Chicago, IL. 2016.
2. Ralston JD, Lim C. Understanding What Is Most Important to Individuals with MCCs: A Qualitative Study of Patients' Perspectives. Webinar for the Steering Committee of the AGING Initiative. January 24<sup>th</sup>, 2018.

### Manuscripts in Preparation:

Berry ABL, Lim C, Hartzler A, Wagner E, Ludman E, Hirsch I, Ralston J. Supporting Communication About Values Between People with Multiple Chronic Conditions and their Providers. In submission to Conference on Human Factors in Computing Systems (CHI) 2019.

### Website:

<http://vitalresearchstudy.org>.